

The Economic Value of Informal Caregiving

by Peter S. Arno, Carol Levine, Margaret M. Memmott

In a major policy initiative the Clinton Administration has proposed a \$6 billion five-year package to begin to address the long-term care needs of people with chronic illness or disabilities and their families.¹ By explicitly recognizing that family members are the core long-term care providers in the U.S. health care system, this initiative opens a long-overdue policy discussion.

Because "informal" caregiving lies outside the market economy and is socially and politically invisible, its economic value is not generally acknowledged. Although some aspects of families' contributions to patient care are impossible to measure (such as the comfort of being cared for at home), other aspects can be expressed quantitatively. This study addresses one such question: What is the current market value of the unpaid caregiving provided by family members and friends to adults who are chronically or terminally ill or seriously disabled? There have been some limited attempts to arrive at such a number,² but no recent systematic estimates.³ This study begins to fill that gap.

Study Methods

We analyzed two key questions: (1) What is the national prevalence of informal caregiving and (2) What is a reasonable market wage that would have to be paid to replace informal caregiving?

Prevalence and definitions. National prevalence figures were derived in two steps: (1) estimating the number of informal caregivers and (2) determining the hours of care

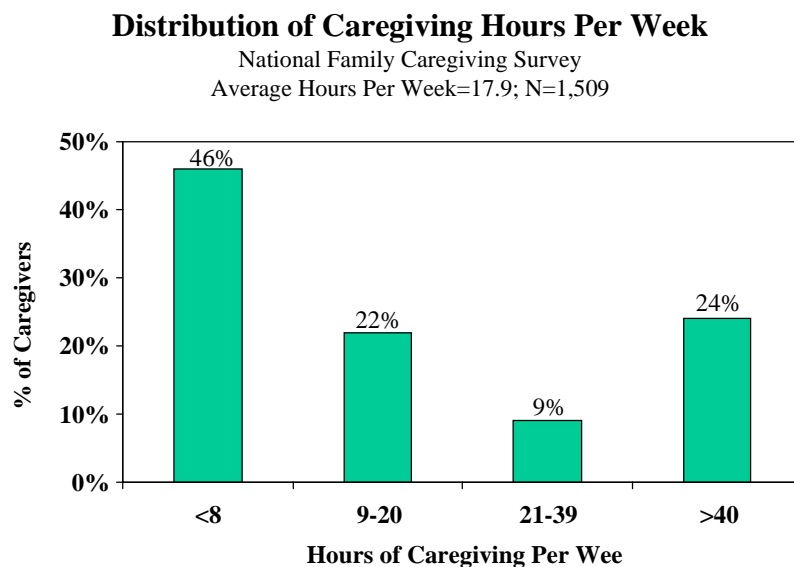
provided per caregiver. For the former we examined a variety of national datasets including the Survey on Income and Program Participation (SIPP), the National Survey of Families and Households (NSFH), the National Health Interview Survey (NHIS), and the National Long-Term Care Survey (NLTC). Because SIPP and the NSFH provided the most comprehensive data on the prevalence of caregiving in the general population, we used these surveys and their definitions of caregiving to develop our estimates. (The NLTC includes only Medicare patients over the age of sixty-five.)

SIPP is a national, multi-panel, longitudinal survey of adults, representative of households in the civilian, noninstitutionalized population.⁴ The 1986 survey wave collected information from approximately 19,100 households on whether persons age fifteen or older needed or provided personal assistance with everyday activities. A person was considered to need personal assistance only if his or her limitation was the result of a health condition that had lasted or was expected to last three months or longer. We assumed that the ratio of caregivers to the U.S. population, by age cohorts, was the same in 1997 as in 1986. This yielded an estimated twenty-four million caregivers in 1997.

The first wave of the NSFH included a national probability sample of 13,017 noninstitutionalized American adults in 1987 and 1988.⁵ Respondents were asked about the need for or provision of personal assistance due to a disability or chronic illness. A similar approach was used to estimate the number of caregivers as described above. The number of caregivers providing personal assistance to adults (age eighteen or older) was disaggregated by sex: 11.3 million men and 16.1 million women. Assuming that the ratio of caregivers to the general population by age and gender was the same in 1997 as in 1987-88, this yielded an estimated 27.6 million caregivers in 1997.

Number of caregiving hours. The best overall source of data for estimating the number of caregiving hours in the general population was found in the National Family Caregiving Survey (NFCS).⁶ Fielded in 1996, the survey was based on a nationally representative sample of 1,509 English-speaking households with telephones. This survey yielded an average of 17.9 caregiving hours per week. The distribution of caregiving hours reported in the NFCS is shown in Exhibit 1. This figure was used in this analysis because of the general nature and size of the sample; because of the lack of better estimates from larger, more comprehensive surveys; and because it is a conservative estimate that is lower than found in most other published studies.

Exhibit 1



Most studies reporting hours of informal caregiving targeted relatively disabled and chronically ill elderly individuals or used small samples focusing on specific medical conditions. Ernst and Hay estimated the number of unpaid caregiver hours from nine studies of community-dwelling demented or mentally impaired patients at 52.5 hours per week.⁷ In

small-sample studies of Alzheimer's disease patients, ventilator-dependent patients, and Parkinson's disease patients, investigators reported an average of 70, 58.8 and 22 hours per week, respectively.^{8, 9, 10}

Wage rate. Two general approaches have been used in the literature. The first entails measurement of the opportunity costs to caregivers of lost or foregone wages and benefits as a result of caregiving responsibilities.¹¹ This approach is not used here because considerable caregiving is provided by retired persons. Thus, to impute their economic worth only from foregone earnings would undervalue their contribution. The second approach, which we have chosen, applies a market wage rate to caregiving activity.¹² Because our main focus is estimating the potential cost in today's market if informal caregiving had to be replaced by paid workers, we selected a wage rate that is more reflective of the current labor market.

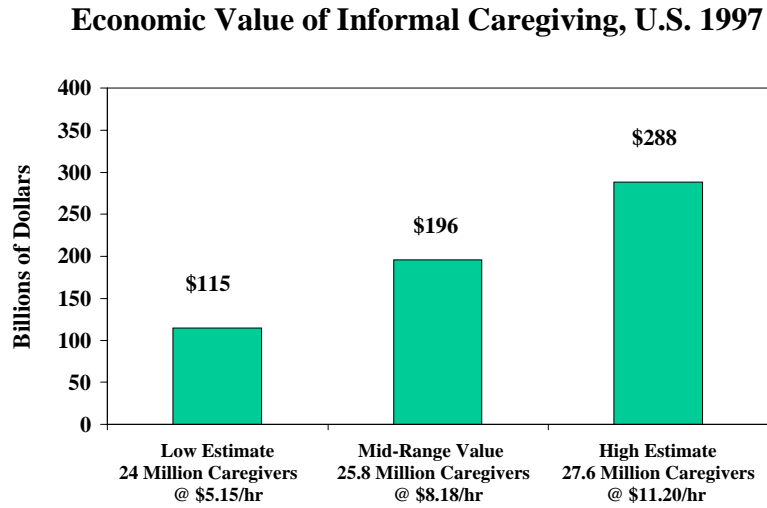
Initially two wage rates were considered: the current minimum wage (\$5.15/hour) and the average, national rate for home health aides (\$11.20/hour).¹³ Because caregiving tasks performed by family members range from the relatively unskilled to the highly skilled, we chose \$8.18/hour as a midrange wage rate. This figure does not include benefits or administrative overhead required for formal employment.

Findings

Caregiving prevalence estimates derived from large, distinct, national data sets generated a narrow range of estimates for the number of caregivers in 1997 – 24 to 27.6 million. The midrange estimate is 25.8 million.¹⁴ Applying the average weekly figure of 17.9 hours of informal caregiving to the number of estimated caregivers yields approximately 22 to 26 billion hours of caregiving per year, nationwide, with a midrange estimate of 24 billion hours. Using

midrange figures, the national economic value of informal caregiving was \$196 billion in 1997 (Exhibit 2).

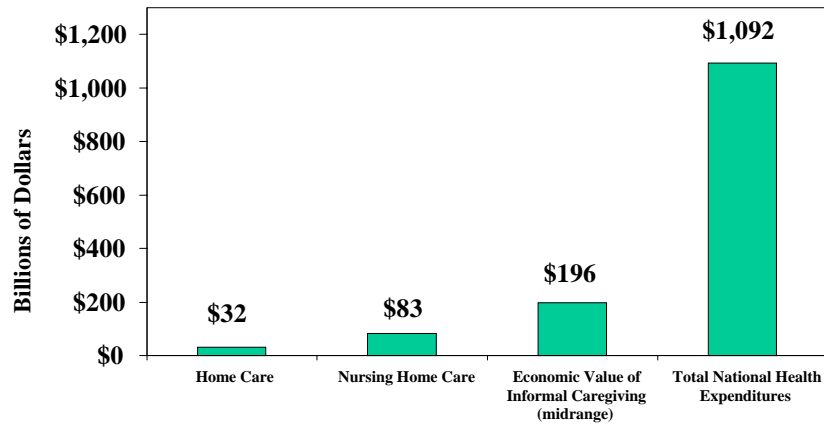
Exhibit 2



The economic value of informal caregiving in 1997 dwarfs national expenditures for formal home health care (\$32 billion) and nursing home care (\$83 billion) (Exhibit 3). At the midrange estimate of \$196 billion annually, the economic value of informal caregiving is equivalent to approximately 18% of total national health care expenditures. Informal caregiving is not counted as part of national health care expenditures. If it were, the trillion-dollar figure would rise by nearly \$200 billion.

Exhibit 3

Home Care, Nursing Home Care, Informal Caregiving & National Health Expenditures, U.S. 1997



Expenditure data from HCFA, Office of the Actuary, National Health Statistics Group, 10/29/98.

Using the same methods, we calculated the number of caregivers, caregiving hours and the estimated economic value on a state-by-state basis (Exhibit 4). The five states with the highest estimated economic value are California (\$22.9 billion), Texas (\$13.6 billion), New York (\$13.5 billion) Florida (\$11.2 billion) and Pennsylvania (\$9.1 billion).¹⁵

Exhibit 4 Estimated Value of Informal Caregiving, Number of Informal Caregivers and Caregiving Hours by State, 1997

	Mid-Range Value (millions of dollars)	Caregivers (millions)	Caregiving Hours (millions)		Mid-Range Value (millions of dollars)	Caregivers (millions)	Caregiving Hours (millions)
Alabama	3,221.8	423,143	393.9	Nebraska	1,201.4	157,788	146.9
Alaska	410.0	53,852	50.1	Nevada	1,225.4	160,942	149.8
Arizona	3,243.4	425,977	396.5	New Hampshire	870.4	114,322	106.4
Arkansas	1,851.6	243,189	226.4	New Jersey	6,059.2	795,802	740.7
California	22,914.3	3,009,523	2,801.3	New Mexico	1,216.8	159,811	148.8
Colorado	2,853.4	374,758	348.8	New York	13,525.3	1,776,382	1,653.5
Connecticut	2,476.5	325,253	302.7	North Carolina	5,508.7	723,498	673.4
Delaware	549.3	72,140	67.1	North Dakota	469.6	61,671	57.4
Florida	11,214.6	1,472,899	1,371.0	Ohio	8,298.3	1,089,878	1,014.5
Georgia	5,422.7	712,203	662.9	Oklahoma	2,422.5	318,164	296.1
Hawaii	874.6	114,872	106.9	Oregon	2,422.1	318,200	296.2
Idaho	844.0	110,845	103.2	Pennsylvania	9,155.1	1,202,411	1,119.2
Illinois	8,651.4	1,136,260	1,057.6	Rhode Island	749.8	98,473	91.7
Indiana	4,327.1	568,307	529.0	South Carolina	2,777.6	364,803	339.6
Iowa	2,115.6	277,860	258.6	South Dakota	534.1	70,144	65.3
Kansas	1,887.6	247,912	230.8	Tennessee	4,021.2	528,142	491.6
Kentucky	2,921.3	383,673	357.1	Texas	13,636.0	1,790,931	1,667.0
Louisiana	3,119.2	409,665	381.3	Utah	1,316.9	172,955	161.0
Maine	941.9	123,712	115.2	Vermont	441.0	57,916	53.9
Maryland	3,803.5	499,539	465.0	Virginia	5,033.5	661,094	615.3
Massachusetts	4,645.9	610,184	568.0	Washington	4,113.6	540,272	502.9
Michigan	7,207.8	946,663	881.2	Washington D.C.	419.6	55,104	51.3
Minnesota	3,403.7	447,037	416.1	West Virginia	1,401.5	184,065	171.3
Mississippi	1,950.0	256,115	238.4	Wisconsin	3,791.8	498,009	463.5
Missouri	3,974.1	521,950	485.8	Wyoming	343.8	45,161	42.0
Montana	646.5	84,904	79.0				
				TOTALS	196,426.7	25,798,370	24,013.1

Prepared for the Alzheimer's Association.

Implications

Spurred by concerns of consumers and health care professionals, policy makers at both state and federal levels are beginning to investigate the unmet needs of family caregivers. The U.S. Senate Select Committee on Aging, for example, held the first Congressional hearing on caregiving in September 1998. New Jersey's Governor Whitman recently created an Elder Care Task Force, which also held a hearing on caregiving. The National Health Council is developing an action agenda on caregiving for the next three to five years.

Imputing an economic value to the extraordinary level of caregiving described in this study does not detract from the emotional, cultural and societal values expressed through

informal caregiving. On the contrary, it enhances their importance by providing a tangible measure of the vast but vulnerable base upon which our chronic care system rests.

Toll on individuals, families and society. Caregiving has become a normative experience. While it may bring personal gratification to some, it clearly takes a well-documented toll on many caregivers' physical and mental health.^{16,17,18,19,20,21,22,23,24} The costs are not only to the individual, however. Stress and exhaustion may lead to increased health care resources being devoted to the caregiver as well as the patient, and may exacerbate family destabilization and impoverishment. Families undergo serious social and emotional as well as financial disruptions when caregiving competes with and often overwhelms all other family needs and interests. These are concerns not only for individuals and families but also for the larger society. As the population ages and as chronic conditions continue to account for a high proportion of medical costs, these concerns will become even more critical.^{25,26}

This study has explored only one aspect of the economic impact of family caregiving. Other studies have addressed the substantial direct costs families pay in unreimbursed health care expenses, even if they are insured.²⁷ Other important factors are the loss of income and other benefits, such as Social Security, when a caregiver gives up a job or reduces hours of work.²⁸

Policy Options. Our focus on the economic value of informal caregiving should not be interpreted as an argument to pay caregivers. Neither do we dismiss it as a policy option. Several states already have some limited programs in place to pay informal caregivers.²⁹ Paying some categories of informal caregivers under clearly defined circumstances may provide a level of flexibility and continuity that is difficult to attain in the formal system.

Beyond the tax credits and state information and referral programs outlined in the Administration's proposal, other policy options include amending the Family Medical Leave Act to make it more accessible to employees in small businesses and to make its benefits better known to eligible workers. Social Security credits might also be given to caregivers who take time off from paid employment.

Need for caregiver support. Because family caregivers are not typically part of policy discussions, the limitations of their ability to provide care and their needs for training and support are not usually considered when decisions are made about how to deliver care or save money. Informal caregivers are seldom adequately trained and almost never offered appropriate follow-up services, reevaluation of care arrangements, or referrals to community services. They are left to negotiate an increasingly complex and fragmented system and to find whatever help they can by whatever means they can. No other sector of the health care economy that provides so much valuable care would be neglected in this way.

Policy makers are fearful of the "woodwork" effect if they expand or institute caregiver services. There is no evidence to indicate that caregivers given a helping hand abandon their relatives or take advantage of the system. Most caregivers ask only for training, support, and occasional respite.

Spending for formal home health care has grown dramatically in recent years – more than three times faster than hospital or physician services between 1990 and 1997.³⁰ Efforts to constrain this growth by better management and monitoring are justified. However, reducing costs by cutting vitally needed services will only add to the already heavy burden on informal caregivers.

Informal caregiving has generally been understood only at the micro level of individual caregivers or selected groups of caregivers. This study broadens the issue to the

macro level of the health care system, which must find more effective ways to support and sustain the family caregivers who are the bedrock of our nation's chronic health care system.

Authors

Peter S. Arno, PhD, Professor, Department of Epidemiology and Social Medicine, Montefiore Medical Center/Albert Einstein College of Medicine, 111 E. 210 Street, Bronx NY 10467; phone: 718-652-4631; fax: 718-654-7305; e-mail: parno@montefiore.org

Carol Levine, Director, Families and Health Care Project, United Hospital Fund, 350 Fifth Avenue, 23rd Floor, New York, NY 10118; phone: 212-494-0755; fax 212-494-0823; e-mail: clevine@uhfnyc.org

Margaret M. Memmott, MPH, Research Assistant, Department of Epidemiology and Social Medicine, Montefiore Medical Center/Albert Einstein College of Medicine, 111 E. 210 Street, Bronx NY 10467; phone: 718-920-4751; fax: 718-654-7305; e-mail: mmm91@columbia.edu

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Notes

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⁴ C.L. Harpine, J.M. McNeil, and E.J. Lamas, "The Need for Personal Assistance with Everyday Activities: Recipients and Caregivers." *Current Population Reports. Household Economic Studies. Series P-70, No. 19, 1990*. These activities included help in 1) taking care of personal needs such as dressing, eating or personal hygiene; 2) getting around the household; 3) doing light housework such as washing dishes, straightening up, or light cleaning; 4) preparing meals or; 5) keeping track of bills and/or money.

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